Guideline scope

Models of service delivery for people with learning disabilities and behaviour that challenges

Topic

The Department of Health in England and the Department for Education have asked NICE to develop a social care guideline on models of service delivery for children, young people and adults with learning disabilities and behaviour that challenges.

Who the guideline is for

- Providers of health and social care services for children, young people and adults with learning disabilities and behaviour that challenges.
- Health and social care practitioners working with children, young people and adults with learning disabilities and behaviour that challenges, and their families and carers.

It will also be relevant to:

- Children, young people and adults with learning disabilities and behaviour that challenges and their families and carers, including people who purchase their own care.
- Commissioners of health and social care services for children, young people and adults with learning disabilities and behaviour that challenges.
- Practitioners working with children, young people and adults with learning disabilities and behaviour that challenges in related services, including housing, employment, education and housing.
• Providers of related services, including housing, education, employment
  and criminal justice services

NICE guidelines cover health and care in England. Decisions on how they
apply in other UK countries are made by ministers in the Welsh Government,
Scottish Government, and Northern Ireland Executive.

**Equality considerations**

NICE has carried out an equality impact assessment during scoping. The
assessment:

• lists equality issues identified, and how they have been addressed
• explains why any groups are excluded from the scope, if this was done.

1 What the guideline is about

1.1 Who is the focus?

Groups that will be covered

Children, young people and adults with mild, moderate, severe or profound
learning disabilities¹ and behaviour that challenges, and their families and
carers.

Groups that will not be covered

• Adults with learning disabilities whose behaviour that challenges may be
  attributed to dementia.

¹ The NICE clinical guideline on challenging behaviour and learning disabilities specifies that:
'A learning disability is defined by 3 core criteria: lower intellectual ability (usually an IQ of less
than 70), significant impairment of social or adaptive functioning, and onset in childhood.
Learning disabilities are different from specific learning difficulties such as dyslexia, which do
not affect intellectual ability.' This definition of challenging behaviour and learning disabilities
will also be used in this guideline.
1.2 **Settings**

**Settings that will be covered**

- The guideline will cover models of service delivery for children, young people and adults, provided or commissioned by health or social care, in whatever care setting the person receives care and support, including:

**Inpatient settings**

- Specialist learning disability assessment and treatment units
- Adult mental health and learning disability inpatient settings (including secure settings).
- Older people’s mental health and learning disability inpatient settings
- Children’s mental health and learning disability inpatient settings (including tier 4 CAMHS and secure settings)

**Care home settings**

- All residential and nursing care homes.
- Care homes for children (including secure children’s homes)

**Community settings**

- People’s own homes and other housing, including temporary accommodation.
- Foster care
- Extra care housing (such as warden-supported, sheltered or specialist accommodation).
- Shared Lives Scheme (formerly Adult Placement Scheme) living arrangements.
- Supported living.
- Day care settings.
- Residential schools.
1.3 Activities, services or aspects of care

Key areas that will be covered

We have produced a guideline on prevention and interventions for people with learning disabilities whose behaviour challenges. This new service guideline will focus on how services are organised and configured to deliver these interventions effectively. The guideline will cover:

1. Models of service delivery
2. Service capacity
3. Location of services
4. Types of service provision (including alternatives to inpatient provision)
5. Timely access to services
6. Timely access to staff with a given competency or skill
7. Integration of health and social care services for people with learning disabilities and behaviour that challenges
8. Joint working with related services, including:
   - Housing
   - Education
   - Employment
   - Criminal justice services
9. Safeguarding
10. Risk management

Areas that will not be covered

1. Treatment, therapy, prevention and management of behaviour that challenges in people with learning disabilities. This is covered in NICE’s guideline on prevention and interventions for people with learning disabilities whose behaviour challenges.

1.4 Economic aspects

We will take economic aspects into account when making recommendations. We will develop an economic plan that states for each review question (or key area in the scope) whether economic considerations are relevant, and if so
whether this is an area that should be prioritised for economic modelling and analysis. We will review the economic evidence and carry out economic analyses, using a public sector perspective, as appropriate.

1.5 **Key issues and questions**

While writing this scope we have drafted the review questions listed below. Please note these are only example questions. A full list of review questions covering all of the key areas and issues in the scope will be agreed by the Guideline Committee at the start of guideline development.

1 Models of service delivery
   - What models of service delivery are effective and cost-effective for people with learning disabilities and behaviour that challenges?

2 Service capacity
   - What is the appropriate inpatient bed capacity to facilitate service user flow for people with learning disabilities and behaviour that challenges?

3 Types of service provision
   - What types of community-based provision are effective and cost-effective for people with learning disabilities and behaviour that challenges?

4 Integration of services
   - What mechanisms enable effective joined-up working between service providers supporting people with learning disabilities and behaviour that challenges and their families and carers?

5 Timely access to service
   - What models of delivery facilitate timely access to services for people with learning disabilities and behaviour that challenges?
1.6 Main outcomes

The main outcomes that will be considered when searching for and assessing the evidence are:

1 Person-focused outcomes:
   - Service user and carer satisfaction
   - Mental wellbeing and psychological health outcomes.
   - Health and social care related quality of life.
   - Involvement of people using services, their families and carers in the planning, delivery and monitoring of services.
   - Inclusion in community life.
   - Capability to achieve desired, person-centred outcomes as listed in the 9 areas of wellbeing set out in the Care Act 2014.
   - Carer stress and resilience.
   - Continuity of care.

2 Service-focused outcomes
   - Use of seclusion.
   - Use of manual restraint.
   - Use of psychoactive medication.
   - Use of inpatient placements (including out-of-area placements).
   - Extent to which general and complex physical and mental health needs are met.
   - Timely discharge: length of hospital stay; delayed transfers of care from hospital.
   - Availability, access and uptake of local services.
   - Use of health and social care services (primary and secondary; inpatient, residential and community).
   - Level and type of support from care workers and carers.
Links with other NICE guidance, NICE quality standards and NICE Pathways

2.1 NICE guidance


NICE guidance about the experience of people using NHS services

NICE has produced the following guidance on the experience of people using the NHS. This guideline will not include additional recommendations on these topics unless there are specific issues related to people with learning disabilities and behaviour that challenges:

- Service user experience in adult mental health (2011) NICE guideline CG136.

NICE guidance in development that is closely related to this guideline

NICE is currently developing the following guidance that is closely related to this guideline:

- Transitions between inpatient hospital settings and community or care home settings for adults with social care needs, NICE guideline. Publication expected November 2015.
- Transitions from children to adult services NICE guideline. Publication expected February 2016.
2.2 **NICE quality standards**

NICE quality standards that may use this guideline as an evidence source when they are being developed or updated:

- Supporting people to live well with dementia (2013) NICE quality standard QS30.

2.3 **NICE Pathways**

When this guideline is published, the recommendations will be added to NICE Pathways. NICE Pathways bring together all related NICE guidance and associated products on a topic in an interactive topic-based flow chart.

3 **Context**

**Key facts and figures**

Approximately 1 million people in England have a learning disability and of these people it is estimated that 10–17% behave in a way that challenges (Predictors, costs and characteristics of out of area placement for people with intellectual disability and challenging behaviour, Allen et al. 2007). Rates are higher in teenagers and people in their early 20s.

The most commonly used definition of behaviour that challenges is 'behaviour of such an intensity, frequency or duration that the physical safety of the person or others is likely to be placed in serious jeopardy, or behaviour which is likely to seriously limit or delay access to and use of ordinary community facilities' (Emerson et al 1987).

The Government strategy, Valuing People Now identified that often these behaviours are the only way that people have of communicating that their
needs are not being met. The report notes that it is essential to address these
behaviours because 'ignoring them may put lives at risk'.

3.1 Current practice

Moving from hospital to community-based support

The exposure of widespread abuse at Winterbourne View in 2011 led to a full
enquiry by the Government. Following that enquiry, a number of national
organisations signed up to the Winterbourne View Concordat, and as part of
that NHS England agreed to ‘review all current hospital placements and
support everyone inappropriately placed in hospital to move to community-
based support as quickly as possible and no later than 1 June 2014’. Progress
has been slow and subsequent reporting showed that only 260 out of 2577
people in hospital with learning disabilities and challenging behaviour had a
planned transfer date. Only 172 transfers happened before the 1 June 2014
deadline.

Not everyone in hospital is inappropriately placed: and some may be under
treatment orders from the ministry of justice. However, there are still a large
number of people who do not have a planned transfer date from the date of
admission.

Transforming care – next steps

A report by the Transforming Care and Commissioning Steering Group
chaired by Stephen Bubb (2014) stated that clinicians ‘are being asked to
keep people in the community or discharge to the community when many will
worry that the community-based support on offer is insufficient, or not there at
all’.

Out-of-area placements

The Department of Health (Winterbourne View: good practice examples)
notes that sending people to placements out of area can cause ‘real harm to
individuals by weakening their relationships with family and friends and taking
them away from familiar places and community. It can damage continuity of
care. It can also mean putting people into settings that they find stressful or
frightening. This can damage mental health or increase the likelihood of challenging behaviour arising'.

Feedback from 13 learning disabilities commissioners found that young men with learning disabilities, challenging behaviour and/or autism continue to receive very high cost residential support, often in out-of-area residential care. There is limited evidence of plans to redirect resources to more local service developments. According to the report 54% of people had care plans but only 3% has been given a discharge date. Almost three quarters (71%) of placements were out of area (McGill and Poynter 2012).

**Budget pressures**

The National Audit Office (2015) states that around ‘half of inpatients are funded directly by NHS England. There can be substantial extra costs to local health and care commissioners to meet discharged patients’ community care needs when their hospital care was previously funded by NHS England’. The report highlights that budget pressures have led clinical commissioning groups and local authorities to cut resources for mental health hospitals and community based learning disability teams, including staffing. Some 'specialist learning disabilities teams in the community have been run down, which has contributed to delays in introducing appropriate care packages. This has also increased the risk of hospital admissions, and readmissions, and the pressures on hospital resources'.

The implication of this is that reductions in community services are causing some people to remain in expensive hospital placements longer than is necessary, which is both bad for the person and a poor use of resources.

**3.2 Policy, legislation, regulation and commissioning**

**Policy**

strategy for implementing the change in approach of delivering services set out in it.

The reports from Learning Disabilities Good Practice Project (Department of Health), Improving health and care: the role of the outcomes frameworks (Department of Health) Valuing People Now: Summary Report March 2009 to September 2010 (Good Practice Examples) list several examples of local practice innovations.

This guideline will consider good practice examples as well as draw from the experience and knowledge of the guideline committee to review the effectiveness of different configurations of services and service models. The guidelines will also include the views and experiences of good practice from people using services, their families and carers and practitioners.

Legislation

Listed below are some of the key pieces of legislation and statutory guidance for people with learning disabilities and behaviour that challenges. This is not intended to be an exhaustive list; rather it provides additional context for the guideline work.

- Care Act 2014 setting out the duties and powers of local authorities to provide care and support to people using services and their carers.
- Children Act 1989.
- Care Standards Act 2000.
- Carers and Disabled Children Act 2000
- Mental Health Act 1983 Part II: Compulsory admission to hospital and guardianship.
- Mental Health Act 1983 Part III: Patients concerned in criminal proceedings or under sentence.
- The Mental Capacity Act 2005.
Commissioning

The commissioning of services for people with learning disabilities and challenging behaviour involves local authorities, CCGs and NHS England and can be fragmented. Provision is split between state-run and independent (mostly for profit). Often there is a lack of incentive to discharge and transfer people out of hospital or residential provision.

The Services for people with learning disability and challenging behaviour or mental health needs (Department of Health, 2007) report found that commissioning was 'too reactive', and there is evidence that this still applies. It was noted that decisions to buy services are often made 'on the basis of lowest cost in the short-term, without considering the long-term effects when things go wrong'. Often, local services are still fragmented, disconnected and poorly designed and there is no consistent model for challenging behaviour services applied across the country.

Further information

This is the draft scope for consultation with registered stakeholders. The consultation dates are 15 July to 02 September 2015.

The guideline is expected to be published in September 2017.

You can follow progress of the guideline.

Our website has information about how NICE guidelines are developed.